January 19, 2016

The Honorable Steve Knight
1023 Longworth House Office Building
Washington, DC 20515

RE: H.Res. 586, expressing support for “DIPG Awareness Week”

Dear Representative Knight:

On behalf of the Oncology Nursing Society (ONS), I write to thank you for introducing H.Res. 586, expressing support for the designation of the forth week in May as “DIPG Awareness Week.” Your resolution will raise awareness and encourage research into cures for diffuse intrinsic pontine gliomas (DIPG) and pediatric cancers in general.

As you know, DIPG are highly aggressive and difficult to treat brain tumors found at the base of the brain. They are found in an area of the brainstem that controls many of the body’s most vital functions such as breathing, blood pressure, and heart rate. Approximately 300 children are diagnosed with DIPG each year, usually between the ages of 5 and 9, and the prognosis for DIPG remains very poor. Oncology nurses are the health professionals involved in the administration and monitoring of chemotherapy and managing the associated side effects these cancer patients may experience. Every day, we see the pain and suffering caused by cancer and understand the physical, emotional, and financial challenges that children with cancer, and their families, face throughout diagnosis and treatment.

ONS is a professional organization of over 37,000 registered nurses and other health care providers dedicated to excellence in patient care, education, research, and administration in oncology nursing. ONS’ members are a diverse group of professionals who represent a variety of roles, practice settings, and subspecialties. Our nurses are leaders in the health care arena, committed to continuous learning and leading the transformation of cancer treatment by advocating for high-quality care for our patients.

Please know that ONS and its members very much appreciate your leadership on the issue of pediatric cancer awareness. We would be happy to discuss ways in which ONS may be of assistance in this endeavor, and encourage you to contact Alec Stone, MA, MPA, ONS Director of Health Policy, at astone@ons.org.

Sincerely,

Margaret Barton-Burke, PhD, RN, FAAN
President, Oncology Nursing Society